

# The Human Genome Organisation

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## **MINUTES**

of the fourth meeting of the Council, held on Friday 7th September 1990 at St Giles' House, Oxford, UK

Present:

Walter Bodmer

(President)

[for items 1-6]

Sydney Brenner

Charles Cantor

(Vice-President)

Kay Davies

Malcolm Ferguson-Smith

Victor McKusick

Jean-Louis Mandel Kenichi Matsubara

(Vice-President)

Nobuyoshi Shimizu Edwin Southern

Ronald Worton

By invitation:

Mary Lyon

Robert Sparkes

Michael Morgan

Tony Vickers

David Galas Mark Guyer

(DOE)

(NIH)

(Wellcome Trust)

(MRC)

I for items 11-7

In attendance:

James Wyngaarden

(Director

George J Cahilli

(Treasurer) (Secretary)

Bronwen Loder Diane Hinton

Stephen Herst

Apologies:

Francis Collins

Jean Dausset Leroy Hood Andrei Mirzabekov

Lennart Philipson Frank Ruddle

Glauco Tocchini-Valentini

1. The President welcomed Dr David Galas (US-DOE), Dr Mark Guyer (US-NIH); Dr Michael Morgan (Wellcome Trust); Dr Tony Vickers (UK-MRC); also Dr James Wyngaarden, the recently appointed Director of HUGO, and Mr Stephen Herst, Deputy Administrator, HUGO-Europe. He mentioned that the CEC (DG XII) had been invited to send a representative; Dr Bronwen Loder was representing DG XII on this occasion.

The agenda was adopted with the addition of the following items:

- 13:1 Relationships with Third World countries and UNESCO
- 13.2 Fission yeast project
- 13.3 Brochure
- 13.4 Appointment of staff to Americas office
- 2. The minutes of the third meeting were agreed as a correct record and signed.
- 3. Matters arising from the minutes
  - 3.1 Minute 3: Donation of Condominium by HHMI
    The Council formally <u>resolved</u> to accept the offer made by the Howard Hughes
    Medical Institute of the condominium office at 7986-D Old Georgetown Road,
    Bethesda, Maryland 20814, USA.

The Council further <u>resolved</u> to empower Dr James Wyngaarden to act on behalf of HUGO in effecting this transfer and agreed to be bound by his actions in this particular matter.

- 3.2 Minute 3: Operational Procedures
  - (i) The Council <u>resolved</u> formally to confirm Dr Wyngaarden's appointment as Director of HUGO and further resolved that he was empowered to sign cheques on behalf of HUGO.
  - (ii) The Council also <u>resolved to amend</u>, for a trial period of 1 year, ie until 6 September 1991 paragraph 3.2.1 of the Operational Procedures to read as follows:
  - 3.2.1 Authority to sign cheques should be given to:
    - the President (for all regions)
    - the Chief Executive (for all regions)
    - the Administrators of the regional offices (limited to that region)

The limits to their authority to sign are:

- (i) up to US\$5,000 (or equivalent): the local Administrator;
- (ii) up to US\$20,000 (or equivalent): the President or Director alone;
- (iii) above US\$20,000 (or equivalent) two signatures will be required : one by the President or Director and the second by a Council member;
- (iv) However, where a specific sum for an item of expenditure has been explicitly approved by the Council, the President or Director may sign a cheque for this sum for the specific purpose, even if it exceeds US\$20,000 or the equivalent.

Dr Matsubara reported that registering HUGO in Japan was necessary to obtain taxexempt status. The conditions for registration are very stringent - for instance, capital funding in excess of 2 million yen is essential. An office has now been made available in Osaka and planning for the support of single-chromosome workshops can begin. It is hoped that some support for these workshops may be forthcoming from the Japanese Government, even if the support is not provided through HUGO.

#### 3.4 Minute 4: Newsletter

An initial attempt to use the DOE-NIH Human Genome Newsletter has foundered as there were editorial objections to the content of the HUGO news items. Drs Galas and Guyer thought that this problem could be resolved.

# 3.5 Minute 7: HLA sequencing

It was agreed to ask Drs Jack Strominger, John Trowsdale and Daniel Cohen to look into the possibility of organising a workshop within, say, 1 year. They would be asked to produce a plan, with costings, for such a workshop which could then form the basis for an application for funds. The HUGO office could help with the organisational aspects.

# 3.6 Minute 7: Biodiversity cell/DNA bank

Members agreed to proceed with this along much the same lines. A small group - Drs Cavalli-Sforza, Alan Wilson and Alberto Pilazza - would be asked to plan a workshop, the aim of which would be to produce an application to a funding body, such as NIH. A Third World site would be appropriate for the workshop (and someone from the developing countries should be among the organisers). The opportunity of involving UNESCO, and a number of smaller countries, should be explored. It was noted that the Wellcome Trust has a considerable interest in tropical countries.

Some guidelines for feedback should be established. The organisers might be asked to report in 3-4 months on the feasibility and likely cost of such a workshop, and the workshop itself should take place in 12-15 months.

# 4. Report on action taken

None was reported.

## 5. Financial report

The Treasurer tabled a report of US expenditure for the year (Annex 1), noting that the Wesley Foundation had been a major contributor (and had promised \$15k for the coming year.) Total US expenditure was \$31,000, of which about half was attributable to travel; \$2,700 of he UNESCO grant had been returned. In addition, ICRF had spent £26,294 in the year to the end of August, exclusive of salaries, on the operation of the European office.

HUGO was now provisionally tax-exempt in the US and monies were in process of being transferred to HUGO's own accounts. (Funds have to be deposited in multiples of \$100,000 in different banks to ensure insurance coverage). The HHMI funds are now available and HUGO will soon have access to the Wellcome funds. Finally, the Treasurer warned that although the balance sheet looked healthy, the income provided by HHMI would taper off swiftly and HUGO should look for other sources.

The President reported that the Director's salary would be funded by the three regions, one year at a time. The Americas office would pay for the first year.

The Director said that, in preliminary discussions with NIH and DOE about single-chromosome workshops, the <u>pro rata inclusion</u> of funding for the HUGO person who would run this activity, seemed to be acceptable.

It was agreed that a summary of the overall financial situation would be provided at each Council meeting.

Charles Cantor reported on progress since the last Council meeting, when it was agreed to send letters to Nature and Science (which Nature published but Science refused) setting out HUGO's position in relation to these workshops. At the same time, Dr Cantor wrote to all the HGM chromosome Chairs and Co-Chairs. The response had been entirely favourable. After a meeting with representatives of NIH and DOE, an <u>ad hoc</u> Americas Mapping Committee had been convened to discuss the matter and its report was tabled (Annex 2). This document had been discussed by the NIH and DOE Human Genome Program Committees at their recent retreat and with the HGMW Executive Committee. There was general agreement in both discussions that HUGO was proceeding along the right lines.

In the course of a long discussion, the following points were made:

- HUGO's role was as catalyst or facilitator, and provider of the machinery to manage the workshops efficiently; who submits the application for funding is a subsidiary issue;
- some co-ordination was necessary, in that a single canonical set of workshops was wanted. However, identification of the organisers should proceed, as far as possible, in a "bottom-up" manner. People would not be given a monopoly in a particular chromosome:
- there were considerable worries, perhaps unfounded, about the need to keep these workshops truly international. There was also a need for HUGO to identify efforts going on in countries outside the mainstream (eg Sverdlov, USSR, who had recently written to HUGO about his involvement with chromosome 19);
- there was a need to provide (compatible, portable) databases for these workshops. (Concern was expressed about a proliferation of incompatible ones). Also to provide professional science writers to produce the reports;
- the distribution of results and materials is a concern; the Chromosome 21 workshop may serve as a model;
- a single suitable conference centre in the US may be sought and likewise in Europe (the new Wellcome centre, for example);
- a yearly meeting of all the workshop organisers would be necessary, partly to deal with "global" issues like comparative mapping, technology etc.

It was agreed to proceed as set out in the HUGO Americas document (Annex 2) and to set up a Committee to oversee the operation. This Committee would be composed of members of the Physical Mapping Committee and the HGMW Executive Committee, to be selected by the two Chairmen concerned.

## **Decision**

- (i) To adopt the document (Annex 2) as formal guidelines;
- (ii) To establish a Committee to oversee the activity

(Dr Brenner left the meeting).

# 7. Definition of HUGO's strategy

- 7.1 The discussion was confined to fund-raising. The Director suggested a number of different models to be considered and addressed, viz;:
  - an approach to various countries developing human genome programmes. Support could be by international treaty along the lines of that supporting EMBO, or the US-Israel National Science Foundation Treaty;
  - raising money from companies:
  - an approach to international organisations which have expressed an interest eg CIOMS (Council of International Organisations of Medical Science).

It was agreed that stable sources of funding were a top priority. An approach to the membership was suggested: the President replied that the idea of a subscription had been canvassed earlier and rejected, partly because the amount it would raise was insignificant but also because of the variation in real cost between countries.

The Director was asked to study the matter further and report back to the next Council meeting.

# 7.2 Advice to countries starting up human genome programmes

It was agreed that there was a role for HUGO here, particularly in advising on practical matters such as access to probes, links to databases and use of local genetic material. Encouraging governmental agencies to provide support was a far more problematic area.

(Drs Galas, Guyer, Morgan and Vickers left the meeting)

## 8. Reports from Committee Chairs

# 8.1 Physical Mapping

Gerd-Jan Van Ommen and David Cox have been added to the Committee, the former as Vice-Chair.

#### 8.2 HGMW Executive Committee

This Committee would meet at the end of HGM 10.5 to discuss its future role.

#### 8.3 Mouse

Mary Lyon reported that the Committee had not met since Nancy Jenkinson reported at the last Council meeting. However, there had been some developments of note, the most significant of which was the attempt to launch the "Mammalian Genome Organisation" as a rival to HUGO. (It was not known who was behind this, though the name of Peter D'Eustachio was on one letter). The Mouse Committee wishes to have a good relationship with this new organisation: there will be a discussion at the Fourth International Workshop on Mouse Genome Mapping to be held at Anapolis on 4-8 November.

The Anapolis organisers are complaining of a lack of assistance (particularly secretarial) and it would be helpful if HUGO could provide some. It was agreed to contact the organisers and see if HUGO could offer any help.

The next mouse meeting was to have been in Germany in 1991 but the organiser (Jan Klein) had withdrawn on the grounds that it was impossible to raise funds. It will now be held in the Netherlands.

#### 8.4 Informatics

- (i) There is no functioning Informatics Committee, which is creating a problem. It was agreed to ask Lee Hood if he would like someone else to take it over.
- (ii) Charles Cantor raised the question of HUGO nominating people (from outside the US) to attend a meeting of the NIH-DOE Joint Informatics Task Force on October 11th. It was agreed that suitable nominees were:

John Sulston (UK) S Suhai (Germany) Minoru Kanehisa (Japan)

It was stressed that they were HUGO nominees and not representatives of any particular country.

(iii) There was a need for a Physical Mapping Database Committee. A very large range of advice is required. In particular, it is necessary to develop an effective way to accumulate and organise physical map data as part of the activity planned for HGM 11 and 11.5.

The remit of this Committee will be:

- to define the minimum requirementrs for handling physical map data in such a way that they can be implemented by the time of HGM 11;
- to advise on enhancements to the minimum requirements and to place them in priority order;
- as far as possible, to co-ordinate its efforts with those of all other bodies attemptiong to plan or develop physical mapping databases.

Names put forward as possible Chairmen were Lander, Sulston, Branscomb.

## 8.5 Ethics etc

Victor McKusick said that he had proposed a possible membership at the last meeting, to which Hiraku Takebe (Kyoto) should be added. He had not yet approached any of them. The Director mentioned that he had attended the CIOMS meeting in Japan (which had taken a particularly benign view of the ethical issues)). There he had met the Metropolitan of the Eastern Orthodox Church of India who had stressed that Third World countries very much want to be included in these discussions even if they are not deeply involved in the human genome project.

It was agreed (as had been suggested before) that HUGO could consider what has already been done in this area and produce a book. Apart from that, HUGO's role should be to provide:

- (i) <u>scientific advice</u> ie HUGO could recommend people who would provide a scientific input to a meeting:
- (ii) <u>information</u>: HUGO could keep a list of the various meetings;
- (iii) <u>co-sponsorship</u> of some truly international meetings.

It was also agreed that other names might be added to the membership.

## 8.6 Intellectual Property and Ownership

A letter from Lennart Philipson was tabled. His proposed membership, viz

Dr Norman Carey	(UK)
Dr Henry Erlich	(US)
Dr Peter Garland	(UK)
Dr Mark Pearson	(US)
Ms Dianne Sagner	(US)
Mr Dan Singer	(US)
Dr James Wyngaarden	

+ 1 Japanese representative

was accepted. He also proposed to hold the first meeting in Washington in October or November 1990. Members agreed that Dr Philipson should be asked to look for some sponsorship from industry. However, if economies could be effected by meeting on the October/November dates, the Council would be prepared to support the meeting to the extent of (economy-class) travel and subsistence. If the Council provided support, it would require a deliverable in the form of a report.

- (i) The proposed membership is approved
- (ii) Economy-class travel and subsistence will be paid for the first meeting; costings of subsequent activities are required, as is a report.

# 9. Sponsorship of conferences etc

## 9.1 Human Genome III and IV

The President reported that Human Genome III would be held in San Diego in late November 1991 and IV in Nice. V would again be in the US and VI might be held in Japan.

9.2 Genome Analysis: From Sequence to Function, Frankfurt, 10-12 December 1990

The President reported that this would be a meeting for young European scientists to present their work. Some concern was voiced about the way HUGO's name had been used and the need to state specifically that a meeting was "sponsored" or "supported".

# 10. Relationship with Scientific Journals

It was suggested that this be placed on the agenda for the next meeting. In the meantime, it was noted that the Special Features section of Genomics could be used for HUGO News.

# 11. Report of the ad hoc Credentials Committee

It was reported that, of the 70 applicants, the Committee had put forward 67. To these had been added the 25 complete nomination papers received from the membership by the deadline, giving a total of 92 nominations on the ballot paper. Council members had voted overwhelmingly in favour of 90 as the number to elect (and several had suggested all 92). The only reason for not suggesting all 92 was that it would remove all discretion from the membership, with whom it formally lies. However, a box could be added to the ballot paper, asking members if they wished to elect all 92. It was agreed that this should be done.

It was also agreed to advertise for members again next year - in Nature, and in Science also if it will give a substantial discount.

# 12. Date of next meeting

The following dates will be circulated:

Sunday	9 December 1990	(Frankfurt)
Friday	4 January 1991	(Oxford/London)
Saturday	5 January 1991	(Oxford/London)
Sunday	6 January 1991	(Oxford/London)
Monday	7 January 1991	(Oxford/London)

# 13. Any other business

## 13.1 Relationship with the Third World and UNESCO.

Two papers were tabled:

- (i) Report of a Symposium and Workshop on "Molecular Genetics and the Human Genome Project: Perspectives for Latin America" held at the University of Chile, Faculty of Medicine in Santiago, Chile, June 28-30, 1990.
- (ii) UNESCO's programme in the Human Genome :Workplans for 1990 and 1991 (for information).

There were good scientists in Latin America, labouring under great difficulties, and in need of technical help and resources. They were anxious to initiate collaborative links with scientists elsewhere and to become members of HUGO.

It was agreed that the Council should consider further, at a later date, mechanisms for establishing contact with Third World countries and with UNESCO.

## 13.2 Fission yeast genome project

Lennart Philipson had sent the report of the first meeting to discuss a possible international collaboration on physical mapping and sequencing of the fission yeast, Schizosaccharomyces pombe. A further meeting will be held in March 1991 and Dr Philipson was seeking a contribution towards its cost, as well as a general reaction to the project.

It was agreed that the project was worthy of support but that HUGO, in the light of other calls on funds, was in no position to make a contribution. However, the project should again be discussed at the next meeting.

## 13.3 Brochure

The draft brochure, incorporating members' suggestions, but also with a new Introduction, was tabled. Members were asked to send comments to Bronwen Loder.

# 13.4 Appointment of staff to Americas office

It was agreed to appoint Dr Robert Cook-Deegan, from 1 January 1991, to be responsible for HUGO Americas' activities in relation to chromosome-specific workshops and, in particular, to act as rapporteur for these workshops.